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Conducting research with disabled children and young people in health and social care: ethical considerations.

Short title: Conducting ethical research with disabled children and young people.

Abstract

Background: Rights based approaches to conducting research with children and young people are now widely accepted by those working within the field. Such approaches focus on the voice of the child and are underpinned by a firm recognition that children are experts on their own lives. Despite their participatory rights, disabled children and young people are less likely to take part in research.

Aim: In this article, we draw on doctoral research conducted with disabled children and young people and explore the ethical issues that arose around access and recruitment, consent, anonymity and confidentiality and dealing with sensitive issues. Essentially here we discuss what worked in addition to the challenges that we faced.

Discussion: Issues that arose in the planning and conduct of the research are explored here and recommendations for future researchers are made. Research with disabled children and young people can pose additional ethical challenges and while there is an emerging literature around this aspect of childhood research, it needs further development.

Conclusion: Additional planning and preparation is key in order to ensure that disabled children and young people can participate in research in a meaningful way and research is conducted in an ethical manner.

Implications for practice: This article has clear implications for both research and nursing practice in terms of communicating with disabled children and young people, enabling them to express their views and participate in decisions about their lives.

Key words: disabled, children, young people, research, ethics

Introduction

Since the ratification of the United Nations Convention on the Rights of the Child (UNCRC, 1989) in all but 2 countries worldwide, there has been an increased emphasis on conducting research *with* rather than *on* children. According to Article 12 of the UNCRC, children have the right to express their views and have these views given due weight in accordance with the age and maturity of the child. The right of the child to be heard has subsequently been identified as one of the key fundamental values of the convention (Committee on the Rights of the Child (CRC), 2009) and the Committee has more recently identified that particular attention should be paid to disabled children (CRC, 2016). As a result, the self-reported views and experiences of children are increasingly more evident within research rather than relying on parents and other adults as proxies (Parsons *et al.* 2016). The participatory rights of children, as articulated in article 12, have been widely accepted by health and social care researchers locally, nationally and internationally. Underpinned by the sociology of childhood (James *et al.* 1998), children's agency and citizenship have been similarly recognised. Consequently, it is now generally accepted that children are competent social actors rather than 'adults in the making' and as such should be considered experts on their own lives (Christensen and James, 2008). However, despite their general acceptance, these 'new' perspectives on childhood can create dilemmas and tensions for health and social care researchers in terms of recognising children's competence on one hand and the need to protect them on the other (Balen *et al.* 2006). This has added to the complexity of the ethical issues that arise as a result, particularly as regards recruitment, consent, anonymity, confidentiality and protection from harm. These issues can have particular relevance for disabled children and young people, who may be viewed as even more vulnerable by both gatekeepers and researchers. While the views of disabled children have also been increasingly reported in health and social care literature on an international basis, they are

still less likely to participate or be invited to take part in research than other children (Bailey *et al.* 2014). Stalker, (2012) highlighted that disabled children are children first and foremost and like all children, have the right to have Article 12 realised, a point further reinforced in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006). Article 7 emphasises that disabled children should receive disability and age-appropriate assistance to realise their participatory rights. However, as Adjodhia-Andrews (2016) points out, this does not guarantee that they will be asked to share their views in research.

This paper seeks to add to the literature in this area by critically discussing the ethical issues that arose during the conduct of doctoral research that aimed to explore the experiences of disabled children, young people and their parents in health and social care decisions, the findings of which are published elsewhere (see McNeilly *et al.* 2015 and McNeilly *et al.* 2017).

Methods

Eighteen disabled children and young people with a range of impairments aged 6 years to 28 years from one Health and Social Care Trust in Northern Ireland took part in the study.

Table 1: participant demographics (pseudonyms used).

Name	Nature of Impairment	Communication method
Emma	Cognitive	Verbal communication with limited expression
Jack	Autism	Verbal communication
Jason	Physical/Cognitive	Verbal communication with limited expression

Orla	Physical	Verbal communication with very little speech
Emily	Cognitive	Verbal communication
Lauren	Cognitive	Verbal communication with limited expression
Suzanne	Physical/Cognitive/Autism	Verbal communication with limited expression
Michael	Physical/Cognitive/Autism	Verbal communication with little speech
Catherine	Physical/Cognitive	Verbal communication with limited expression
Louise	Physical/Cognitive	No speech
Natalie	Physical	Verbal communication
Mary	Physical/Cognitive	Verbal communication with limited expression
Mark	Physical/Cognitive	Verbal communication with limited expression
Andrew	Physical/cognitive/sensory	No speech/British Sign Language
Sinead	Physical	No speech
Eoin	Autism	Verbal communication
Conor	Autism	Verbal communication
David	Physical/cognitive	Verbal communication with limited expression

Participants were recruited via 2 local advocacy groups. The research was designed with two disabled young adults employed by local advocacy group who were consulted throughout the research process. Mixed methods included four phases of data collection: parent and professional surveys, parent interviews, a focus group with professionals and finally child/young person interviews using participatory and creative methods, the focus of this paper.

NVivo 8 was used to organise the data, first by structural or broad-brush coding and then second cycle coding (Bazeley, 2007; Saldana, 2009) whereby categories and themes were derived from the initial codes. The qualitative component of the study was underpinned by

phenomenology and the guiding principles of Dahlberg *et al.* (2008) were used to inform the analysis process. Ethical approval was granted from the Queen's University Research Governance Office, the Trust Research Ethics Committee and Office of Research Ethics Committees Northern Ireland (ORECNI, approval number 10/NIR03/26).

Access and recruitment of disabled children and young people who took part

It is widely recognised that to invite children and young people to participate in research one has to approach adult gatekeepers to gain access to them (Huang *et al.* 2016). Children and young people's participation was discussed with parents at the end of the parent interview. This provided an excellent opportunity to provide information about their son or daughter's potential involvement in the study and allay concerns about the information that they might provide about professionals or services, issues around anonymity, confidentiality and what methods might meet their individual needs. It was important to stress that the format was different to the parent interview that was based on talking alone. Of the parents who were interviewed, 13 agreed for their son or daughter also to be interviewed. Ten refused for 2 main reasons - their son or daughter would not have sufficient understanding or communication to take part or they would be too anxious to interact with a researcher because of their autism. Such difficulties of recruiting disabled children and young people have been previously reported (Turner, 2003; Rabiee *et al.* 2005; Kelly, 2007). Children and young people were also recruited via a local participation group - in this case it was the children and young people who first expressed a desire to take part and where necessary, consent was obtained from parents.

Consent or ‘assent’?

The children's rights movement, together with the sociology of childhood (James *et al.* 1998), clearly focuses on the voice and agency of the child. While these concepts firmly underpin current childhood research, they can create dilemmas for health and social care researchers who have a duty to protect children from harm. Thus, issues such as approaching parents as gatekeepers and obtaining parental consent for those young people who lack capacity are necessary and considered to be good research practice (Kelly, 2007; Graham *et al.* 2013).

Gallagher (2009) distinguishes between consent and assent, the former involving an act such as verbal or written agreement in the form of a signature and the latter denoted by the apparent willingness of the participant to take part. Consent implies that the individual giving consent has the capacity to do so. In this study, the assessment of children and young people's capacity to take part in the research was based upon guidance by Alderson and Morrow (2011). The following questions were addressed (see Box 1).

The Royal College of Paediatrics and Child Health (see Modi *et al.* 2014) and Oulton *et al.* (2016) maintain that in cases where children do not have sufficient capacity to provide informed consent, then ‘assent’ should be sought. In this study, ‘assent’ was used to refer to those under 16 years or for those of 16 years or over, deemed to lack capacity by their parent, the researcher or other adult who knew them well. Informed consent was used for those young people of 16 years or more judged to have the capacity to make their own decision to take part as judged by the criteria above. The provision of accessible information, in a variety of formats to meet the diverse needs of children and young people, was key in helping them to make an informed decision about their participation.

Providing accessible information for children and young people

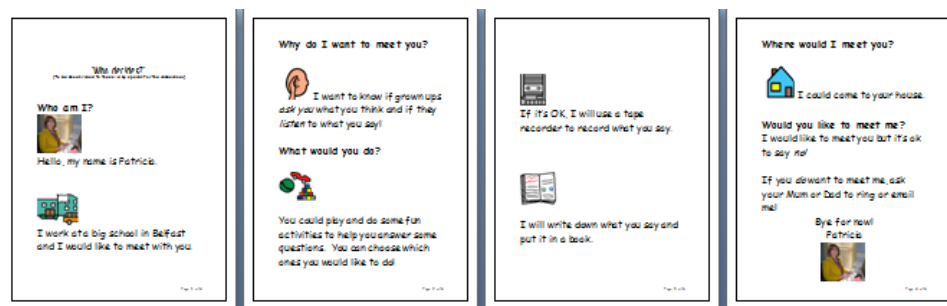
Parsons *et al.* (2016) point out that there are few examples of how information for children and young people has been made more accessible to support their participation in research. In this study, information for children and young people was provided in two formats - firstly in the form of a 'Who Decides?' DVD and secondly in written and/or pictorial format. The aim of the 'Who Decides?' DVD was to provide an alternative means of communicating information to children and young people about their participation in the study. Ensuring that information is accessible and makes sense to participants is widely accepted as good research practice (Graham *et al.* 2013). The 'Who Decides?' DVD used a participatory approach by featuring children and young people from a local voluntary agency group with one young person co-presenting the narrative with the researcher conducting the fieldwork and 2 children demonstrating some of the research activities. Most children and young people saw the DVD before meeting the researcher. Parents seemed to appreciate the range of information for children and young people taking part in the study in terms of content and format. It also provided an opportunity to discuss the types of participatory methods that could be used to help children and young people to express their views. For example, having watched the DVD, parents were able to identify that their child had physical limitations that might restrict their participation in certain activities. Alternatively, they were able to advise that their child liked art and craft materials or were familiar with using Talking Mats®, an interactive, communication resource that uses picture communication symbols (Cameron and Murphy, 2002) . Consisting of 3 elements - a topic, feelings and a number of options, it represents users' views in a clear and straightforward format.

We believe that the DVD made the information more accessible than simply using traditional pen and paper methods. In particular, the fact that children and young people could see what activities they might choose in the course of data collection gave them a better insight and

helped them to make an informed decision about whether or not to participate. However, while the DVD worked well for most children and young people, some lost concentration or chose not to watch it at all. In a study by Parsons *et al.* (2016) some child researchers commented that using technologies to explain the research to children should not replace human communication.


Written/pictorial information was also designed for children and young people. Alderson and Morrow (2004) and Gibson and Twycross (2007) provide useful advice in relation to information leaflets for children and young people and these were used to inform the design of written information in the current study, with input from the two disabled young adults advising on the study. Given the wide age range of children and young people involved in the study, together with their individual cognitive and/or communication impairments, four levels of written information were made available for those taking part in the study. Each included a photo of the researcher but varied in the amount of written information and use of Boardmaker© symbols from levels 1-4 (see Figure 1). Boardmaker© symbols were chosen on the advice of the two young adults who acted as advisors to the study.

Level 1



Level 2

Why do you?
(You are using the Picture Communication Symbols to answer this question.)



Hi, my name is **Parvina**.


I work at **Queen's University** in **Belfast** and I am doing a research project with some children in your area.

I want to know how you feel about the project.

Before we start, I want to know if you want to be in the project. If you don't want to be in the project, I will not ask you any more questions.

Page 2 of 4

What do you want to know?




I want to know if you are happy to be in the project. I want to know if you are happy to be in the project. I want to know if you are happy to be in the project.

What do you want to know?

I want to know if you are happy to be in the project. I want to know if you are happy to be in the project. I want to know if you are happy to be in the project.

Page 3 of 4

What do you want to know?




I want to know if you are happy to be in the project. I want to know if you are happy to be in the project. I want to know if you are happy to be in the project.

What do you want to know?

I want to know if you are happy to be in the project. I want to know if you are happy to be in the project. I want to know if you are happy to be in the project.

Page 4 of 4

What do you want to know?



I want to know if you are happy to be in the project. I want to know if you are happy to be in the project. I want to know if you are happy to be in the project.


What do you want to know?

I want to know if you are happy to be in the project. I want to know if you are happy to be in the project. I want to know if you are happy to be in the project.

Page 5 of 4

Level 3

Why do you?
(You are using the Picture Communication Symbols to answer this question.)




Hi, my name is **Parvina** and I work at **Queen's University** in **Belfast**. I am doing a research project with some children in your area.

I want to know how you feel about the project.

Before we start, I want to know if you want to be in the project. If you don't want to be in the project, I will not ask you any more questions.

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What do you want to know?

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Page 5 of 4

Level 4

What do you want to know?




I want to know if you are happy to be in the project. I want to know if you are happy to be in the project. I want to know if you are happy to be in the project.

What do you want to know?

I want to know if you are happy to be in the project. I want to know if you are happy to be in the project. I want to know if you are happy to be in the project.

Page 2 of 4

What do you want to know?




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Withdrawing consent

Children and young people in the current study were asked how they would like to tell the researcher if they wanted to end the session, for example, they could use a ‘goodbye’ symbol. Some said that they would simply say, although none actually did. Thus, on many occasions the child or young person’s ongoing participation and interest in the research activities and

the use of non-verbal cues was taken as a measure of their assent, an approach taken by other researchers (Kelly, 2007; Parsons *et al.* 2016; Ellis, 2017). Additionally the researcher periodically asked the children and young people if they wanted to continue or do a particular activity.

Anonymity and confidentiality

Anonymity refers to the notion that participants should not be identifiable in research outputs and this is generally achieved by using pseudonyms and ensuring that participants cannot be identified by any personal information presented (Gallagher, 2009). However, when working with disabled children and young people it is also important to be cognisant of individual impairments or communication methods that may identify participants. This was given careful consideration in the reporting of the research. For example, one child was deaf and communicated using sign language, details not used when writing up the findings of the research.

Many researchers maintain that it is their ethical duty to explain the limits of confidentiality to the child at the start of the study (McCrystal, 2008; Twycross *et al.* 2008; Gallagher, 2009). In their review of ethical and methodological issues in health research with children, Huang *et al.* (2016) reported that dilemmas arose around the child's right to privacy versus parents' right to information about their child. In this study, children and young people were told that everything they said would be confidential unless they told me that someone had hurt them or someone else. Alderson and Morrow (2011) point out that while children can expect the same rights to confidentiality as adults, no one has the absolute right to confidentiality where research is concerned. Clearly, variations exist internationally around safeguarding procedures and mandatory reporting of concerns. Arrangements with the local Health and Social Care Trust were that, following discussion with the child or young person,

and if appropriate the parent, the researcher would inform the study supervisors who would notify local safeguarding services if any concerns arose. Children and young people in the study did not disclose any issues that needed such referral; however, they did take the opportunity to talk about issues that were of concern to them and this occurred only when children's parents were not present during the interview. Similarly, Huang *et al.* (2016) reported that children were more likely to talk freely about their concerns when interviewed alone.

At the end of one interview, a 13 year old girl, who used very little speech indicated (via the use of symbols and feelings faces) that she was sad and worried about her grandfather who had a serious health condition. Evidently, her mother was communicating well with her and telling her what was happening, but it was a stressful situation for the young person who was reluctant to share her feelings with her mother:

Researcher: Is mum telling you what's happening with granda?

Orla: Yes.

Researcher: Yes, but you don't really talk to her about your feelings?

Orla: *Don't tell mum.*

Researcher: Don't tell mum?

Orla: No.

It was clear that she wanted to be assured of confidentiality; however, the researcher was relieved to learn that she was confiding with other adults with whom she had ongoing contact. Had the young person in the example above not been talking to someone else, it would have been important to encourage her to do so or make arrangements to discuss with her again. It is not unusual for children and young people to fail to disclose their feelings and

protect their parents from additional stress in such situations (see for example, Price and Cairns, 2009).

Dealing with sensitive issues

While this research did not seek to uncover sensitive issues, building rapport and spending time with disabled children and young people inevitably resulted in issues being disclosed, most often when the child or young person was interviewed alone (as in the example above). Several other sensitive issues arose during field work. For example, when one young person was asked who lived with him, he began to explain that his parents were in the process of getting divorced. On another occasion, one young person said he felt like a burden on his parents and another young person had several siblings who had died. Again, when dealing with such issues it was important to listen and establish if the child or young person was in contact with support services, they had someone to talk to about their feelings or if they wanted the researcher to tell someone how they were feeling. Those interviewing children, therefore, need to expect the unexpected (Macdonald and Greggans, 2008). It had been agreed with the local Health and Social Care Trust that, if necessary, any issues would be referred on to an appropriate professional as all children and young people were in receipt of services at the time of data collection.

Discussion

In keeping with the children's rights agenda, disabled children and young people have the right (and should be enabled) to express their views and have these views given due weight in accordance with their age and maturity. As experts on their own lives, they have the right to participate in research, rather than relying on other adults as proxies. As such, the onus is on researchers to ensure that children and young people are enabled to fully participate. In this

article, we have explored some of the ethical issues that need due consideration when researching with disabled children and young people and make a number of recommendations that arise from this research (see box 2). Clearly it is important for childhood researchers to be transparent, share experiences and learn from each other. Since this study was conducted, the Ethical Research Involving Children (ERIC) project has produced extensive ethical guidance based on 'reflexivity, rights and relationship' (see www.childethics.com). Included is an International Charter for Ethical Research Involving Children, ethical guidance that is evidence based (see Graham *et al.* 2013 and Graham *et al.* 2015), a framework of structured questions, a collection of case studies (including reference to researching with disabled children and young people), an online library and monitored forum. Essentially, ERIC upholds the rights of children in research and seeks to ensure that the dignity of children who take part in research is honoured regardless of context.

While the focus of this paper was conducting research with children and young people, the issues discussed here also have implications for professional practice, specifically around communicating effectively with children and young people. Previous researchers have also discussed how conducting their research with children has highlighted the importance of effective communication in the practice setting (McLeod, 2008; Le Fevre, 2010; Winter, 2011). This article has highlighted the importance of actively listening to children and young people, enabling them to have a voice, providing them with appropriate information and assessing capacity and assessing assent or consent on an ongoing basis, all key issues in nursing practice.

Further research is needed around researchers' and practitioners' communication skills and their ability to meaningfully listen to children (including the use of augmentative communication), their knowledge and skills around the assessment of capacity and ensuring ongoing assent/consent when working with disabled children and young people in the

practice setting. Additionally, more work needs to be undertaken in relation to researchers' experiences of ethical issues when conducting research with disabled children and young people to further identify the challenges as well as what works.

Conclusion

Hearing the views of disabled children and young people is a vital part of the childhood researcher's role. While at times this is no different than researching with other children, enabling disabled children to participate can require additional planning and consideration during data collection. Issues such as access and recruitment, consent and the provision of accessible information, anonymity and confidentiality and dealing with sensitive issues have been considered here and recommendations are made for future researchers.

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Conflict of interests

The authors declare that there is no conflict of interest.

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Box 1:**Questions used to assess capacity**

- Are they able to make a choice and do they understand what it is they are making a decision about.
- Do they know the risks, benefits and alternatives.
- Is consent voluntary
- Is it informed
- Do they know that they can withdraw at any time.

Box 2:**Recommendations for future researchers**

- Consider using a wide range of written/pictorial information for children and young people and enhance accessibility by considering alternative means of information giving.
- Remember that assent and consent is an ongoing process - in particular, be vigilant for non verbal cues and be willing to abandon the interview if the child or young person indicates the withdrawal of their agreement to take part.
- Plan, in advance, how you will address issues that may arise around anonymity and confidentiality.
- Discuss arrangements with stakeholders for safeguarding children should the need arise and dealing with issues around their emotional well-being.
- Listen and respond to any sensitive issues that arise and if necessary work with the child or young person if information needs to be shared or further action taken.
- Where interviews with parents form part of the study, discuss the child or young person's participation at the end of the parent interview. Alternatively, find ways to provide parents whose consent is required with additional information about what will be involved if their child is to take part.
- Expect the unexpected.

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